

The importance of early intervention: an MSer's perspective

George Pepper
Shift.ms

Preparation of *Brain Health: time matters in multiple sclerosis* and its recommendations was funded by an educational grant from F. Hoffmann-La Roche, who had no influence on the content

Support for the MS Brain Health activities and supporting materials has been funded by grants from AbbVie, Actelion Pharmaceuticals and Sanofi Genzyme and by educational grants from Biogen, F. Hoffmann-La Roche and Novartis, all of whom had no influence on the content

A red cable enters from the top left, passes through a dark blue speech bubble containing the name 'George Pepper', and ends in a green hand pointing towards a small figure of a person on the right. The person has a blue head and a grey body. The speech bubble has a small dark blue circle at its tail.

George
Pepper

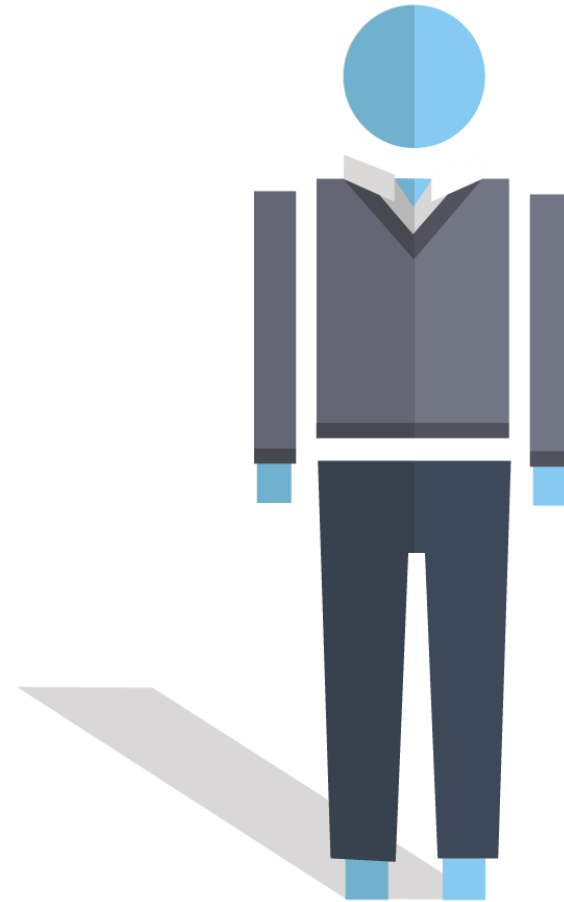
I have MS
I'm not a doctor

george@shift.ms
Leeds, UK

An MSer's perspective



- Diagnosed 12 years ago
- My MS was active early on
- Have received six different treatments



Shift.ms



www.shift.ms is a social network for MSers, particularly the recently diagnosed

Shift.ms is a global community focused on:

- reducing isolation
- MSers acknowledging and actively managing their MS
- creating a self-sustaining community



Consultation
document

Brain health

A guide for people with multiple sclerosis

George Pepper
Helmut Butzkueven
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Neurological reserve

- Once neurological reserve runs out, the brain can no longer compensate



Neurological reserve declines

The finite capacity of the brain to adapt to damage – **neurological reserve** – is slowly used up

Regular monitoring is important

- No longer just relapse rates and EDSS
- Regular MRI scans and clinical assessments too
- Ask what the results mean for you



Live a brain-healthy lifestyle



**Keep physically
active**



**Keep your weight
under control**



**Keep your
mind active**



Avoid smoking



**Watch how much
you drink**



**Take medications
prescribed for
other diseases**

Forum posts about treatment



Treatment
confusion

MS has side
effects too!

New guidelines
re. early
treatment

Which DMD?

Risk perception
and DMTs

Treatment
choices,
**** or ****?

Progression
/Transition
Treatment?

JCV positive

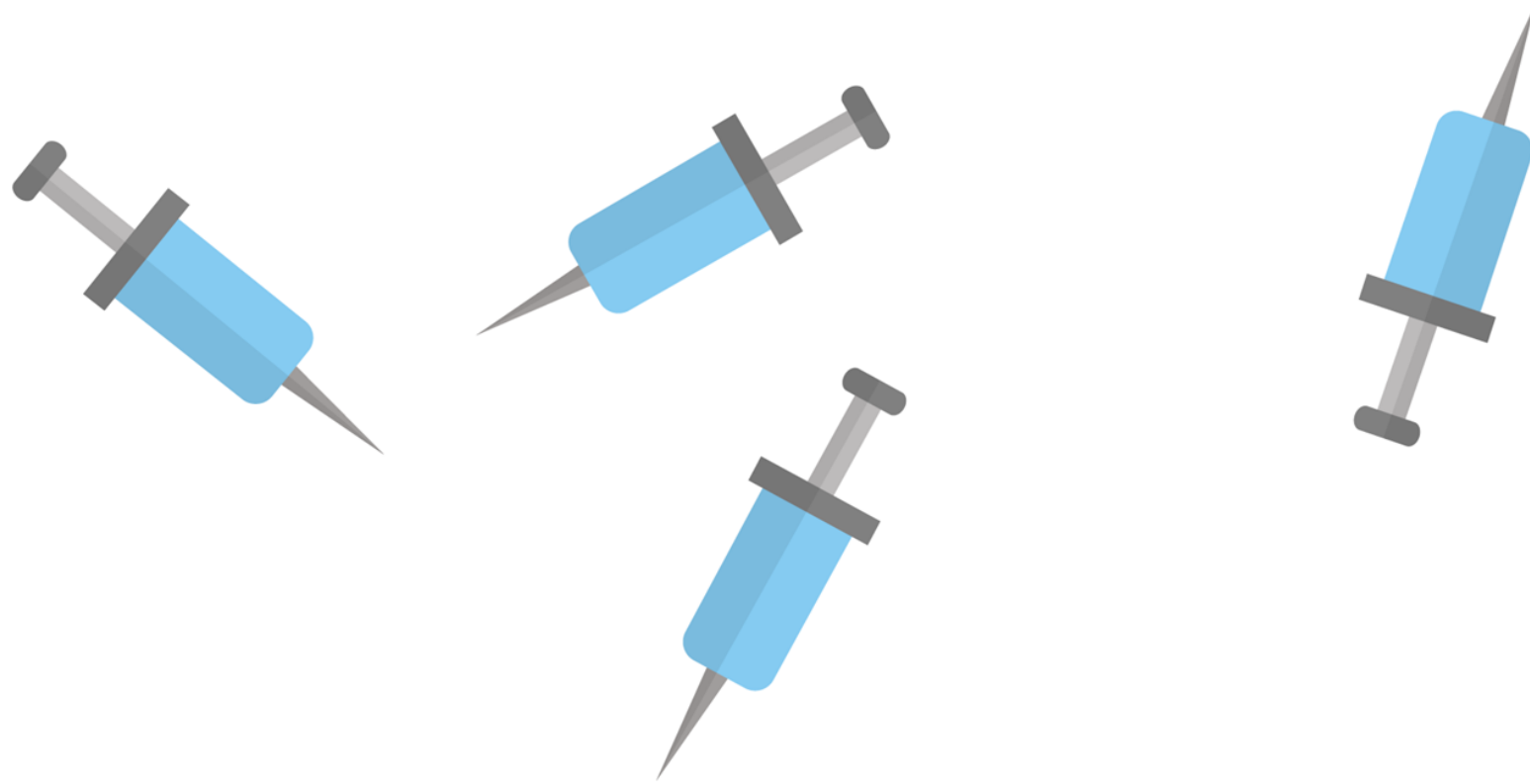
Anyone pregnant
while on DMTs?

Super confused
which 1 to pick?

Coming off ****

**** reviews
water! Anyone
else on this?

The landscape has changed



The landscape has changed



The landscape has changed



MSers have different needs

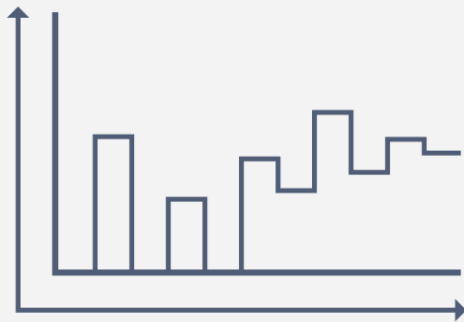


Disease
activity



MSers have different needs

Disease
activity



Lifestyle



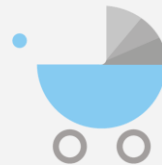
MSers have different needs



Disease
activity



Lifestyle



Attitudes
to risk

Investment risk
profile

Aggressive

Moderate

Conservative

Engaged patients do better



Engaged patients do better

- Learn about MS and the options available to you
- Ask questions to your health professionals
- Be proactive in managing your MS

Engaged patients do better

- Learn about MS and the options available to you
- Ask questions to your health professionals
- Be proactive in managing your MS

*Patient engagement in their own healthcare has been described as the ‘blockbuster drug of the century’.**

* Achieving patient engagement in multiple sclerosis: A perspective from the multiple sclerosis in the 21st Century Steering Group 2015

Summary

- Learn about the brain health perspective and embrace a brain-healthy lifestyle
- Be empowered to ask for regular monitoring and the right treatment for you
- Share the report far and wide!



www.shift.ms

The social network for MSers

Brain health: a guide for people with multiple sclerosis

Professor Eva Havrdová

European Multiple Sclerosis Platform

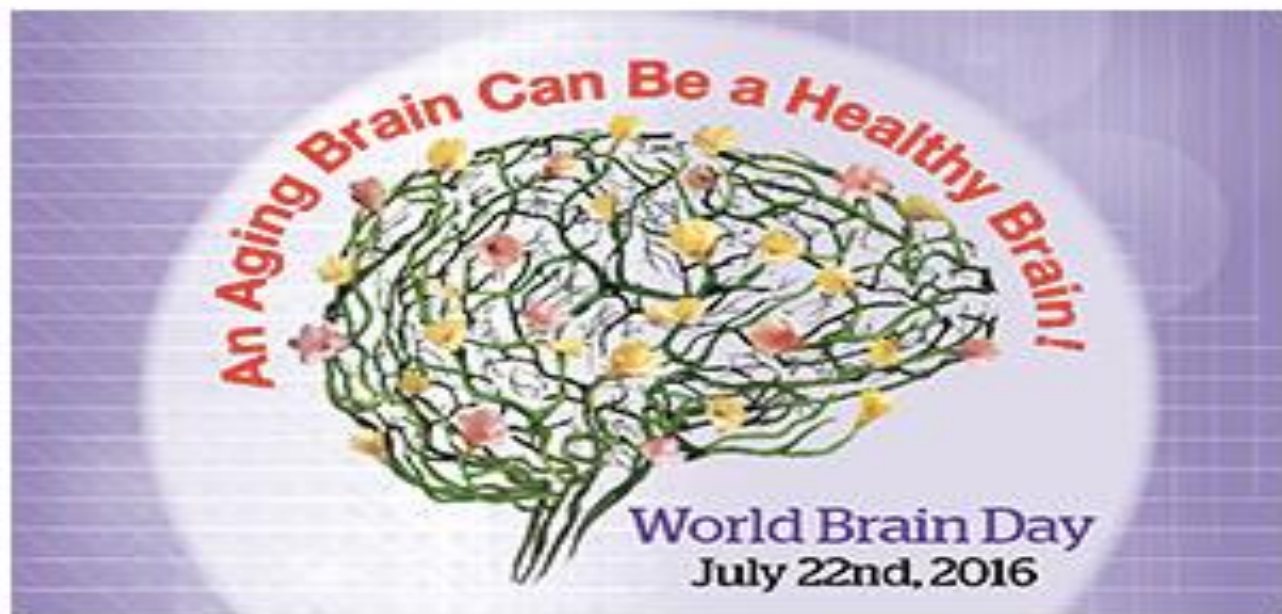
18 May 2016, Oslo, Norway

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FROM THE WFN



World Brain Day 2016

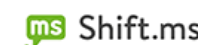
Brain Health in an Aging Population: "The Aging Brain"

By Mohammad Wasay, MD, FRCP, FAAN, and Wolfgang Grisold, MD

The global share of older people (age 60 and over) is more than 800 million (12 percent of the population) and is growing, with the expectation that it will reach more than two billion (21 percent of the population) by 2050. [MORE](#)

Report published October 2015

- Importance of brain health in multiple sclerosis (MS) and the need for urgency at every stage
- Evidence-based international consensus recommendations
- Authored by international experts and endorsed by professional societies and advocacy groups



A short summary for people with MS is now available

■ How the short report can help you

□ Everyone with MS

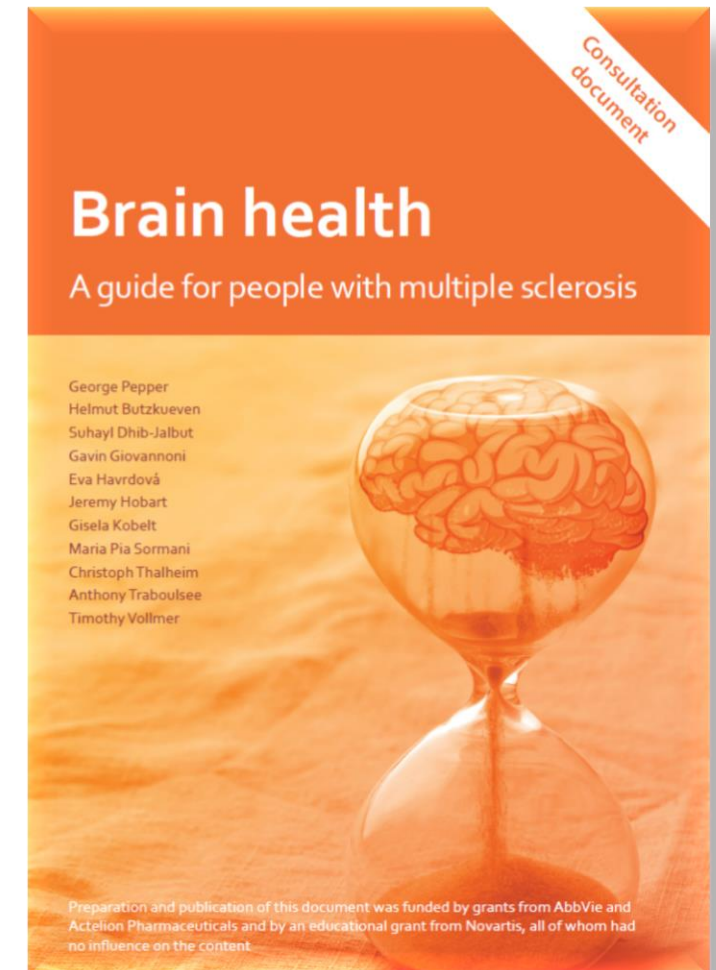
- embrace a 'brain-healthy' lifestyle
- explain to HCPs what matters to you, and make shared decisions
- keep an MS diary of things that affect your health and wellbeing
- feel understood and well informed
- start treatment as early as possible with a DMT (if appropriate)

□ People at/very near to diagnosis

- ask for urgent referral to a neurologist and access to diagnostic services

□ People with relapsing forms of MS

- discuss monitoring of your MS using MRI brain scans
- be confident discussing the possibility that disease activity may be ongoing even when you are feeling well



Recommendations of the short report

- The short report recommends a therapeutic strategy that aims to maximize lifelong brain health that involves:



Understanding the importance of brain health



Living a brain-healthy lifestyle



Earliest possible referral and diagnosis



Monitoring of disease activity



Early treatment with an appropriate DMT



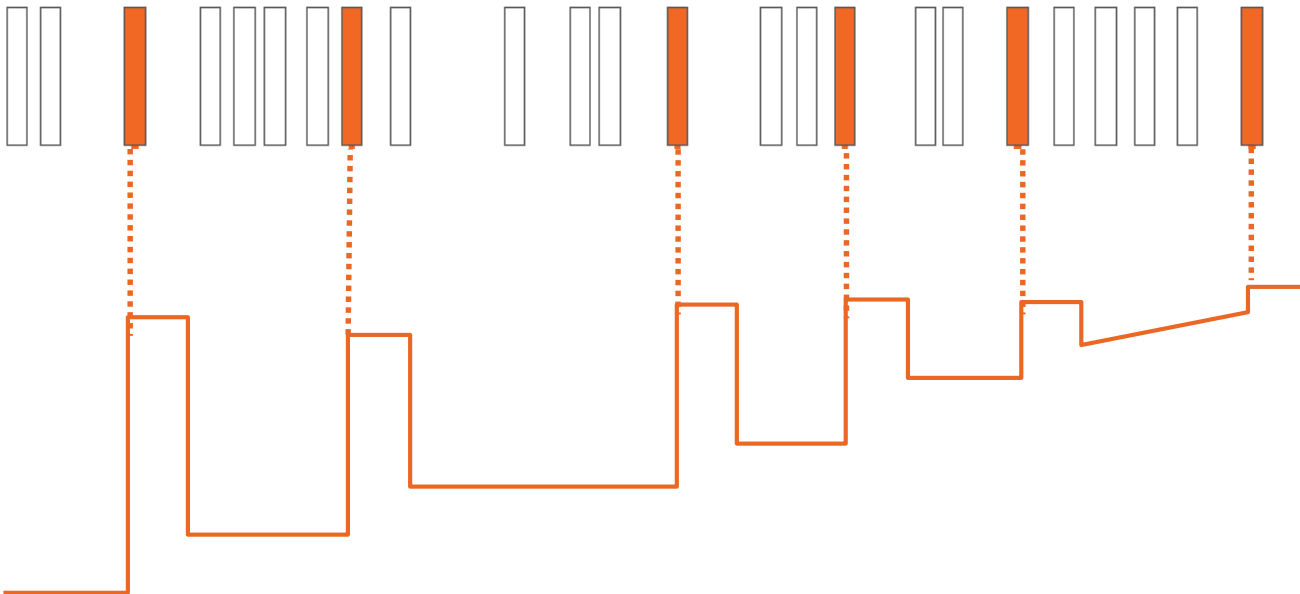
Informed, shared decision-making



1. The importance of brain health



A small amount of brain tissue loss is normal in healthy adults, but in MS this happens faster than usual as a result of the damage caused by disease activity



New lesions appear – all cause tissue loss (white), but some lead to relapses (orange)

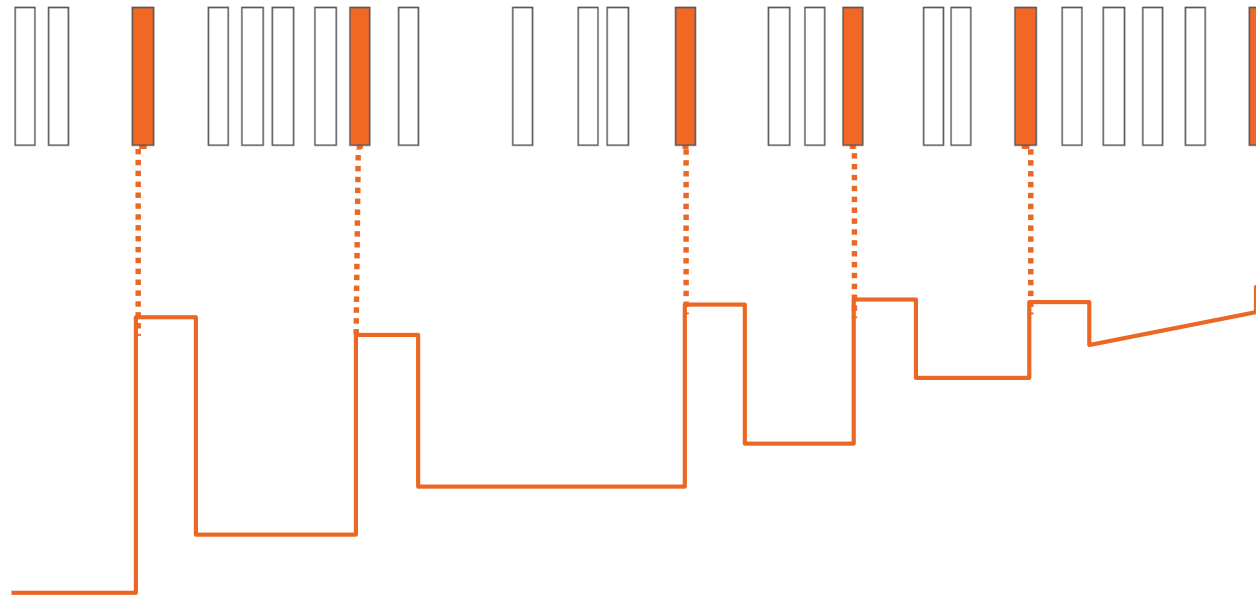


1. The importance of brain health



Neurological reserve declines

The finite capacity of the brain to adapt to damage – **neurological reserve** – is slowly used up



Disability progression is more likely when neurological reserve has been exhausted



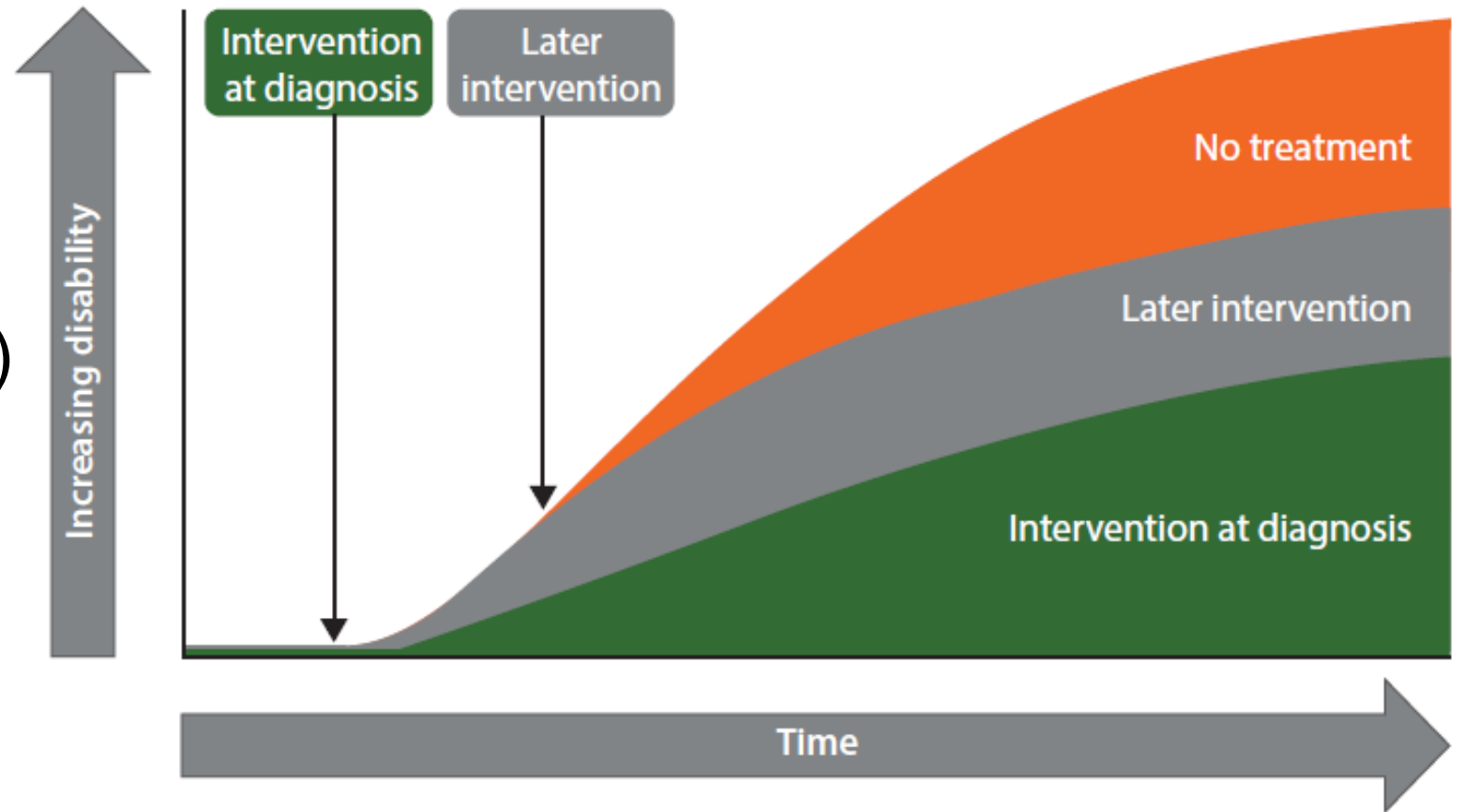
2. Early referral and diagnosis

- Ask for urgent referral to a neurologist, preferably with a special interest in MS, or an MS specialist clinic if the disease is suspected
- Request timely access to diagnostic procedures, including MRI
 - It is now possible to diagnose MS earlier than ever before, owing to evidence from MRI brain scans¹
- Stay in touch with your MS team for ongoing monitoring if you do not receive a diagnosis straight away

3. Early treatment with a disease-modifying therapy: Start treatment as soon as possible



- In people with relapsing forms of MS, starting treatment with a DMT early in the disease course (if appropriate) is associated with better long-term outcomes than delaying treatment ¹



DMT, disease-modifying therapy; HCP, healthcare professional

1. Giovannoni G *et al.* 2015. Appendix 1. Brain health: time matters in multiple sclerosis;57–60.

Adapted with permission from Oxford PharmaGenesis from Giovannoni G *et al.* *Brain health: time matters in multiple sclerosis*, © 2015 Oxford PharmaGenesis Ltd.

3. Early treatment with a disease-modifying therapy: Choose the most appropriate DMT



- Treatment options are rapidly evolving; many DMTs are now available
- Not all DMTs are equally effective in all people with MS; each has particular benefits and possible side effects
- Discuss with your HCPs which is the most appropriate DMT for you



DMT, disease-modifying therapy; HCP, healthcare professional

1. Giovannoni G *et al.* 2015. Appendix 1. Brain health: time matters in multiple sclerosis;57–60.



4. Live a brain-healthy lifestyle



**Keep physically
active**



**Keep your weight
under control**



**Keep your
mind active**



Avoid smoking



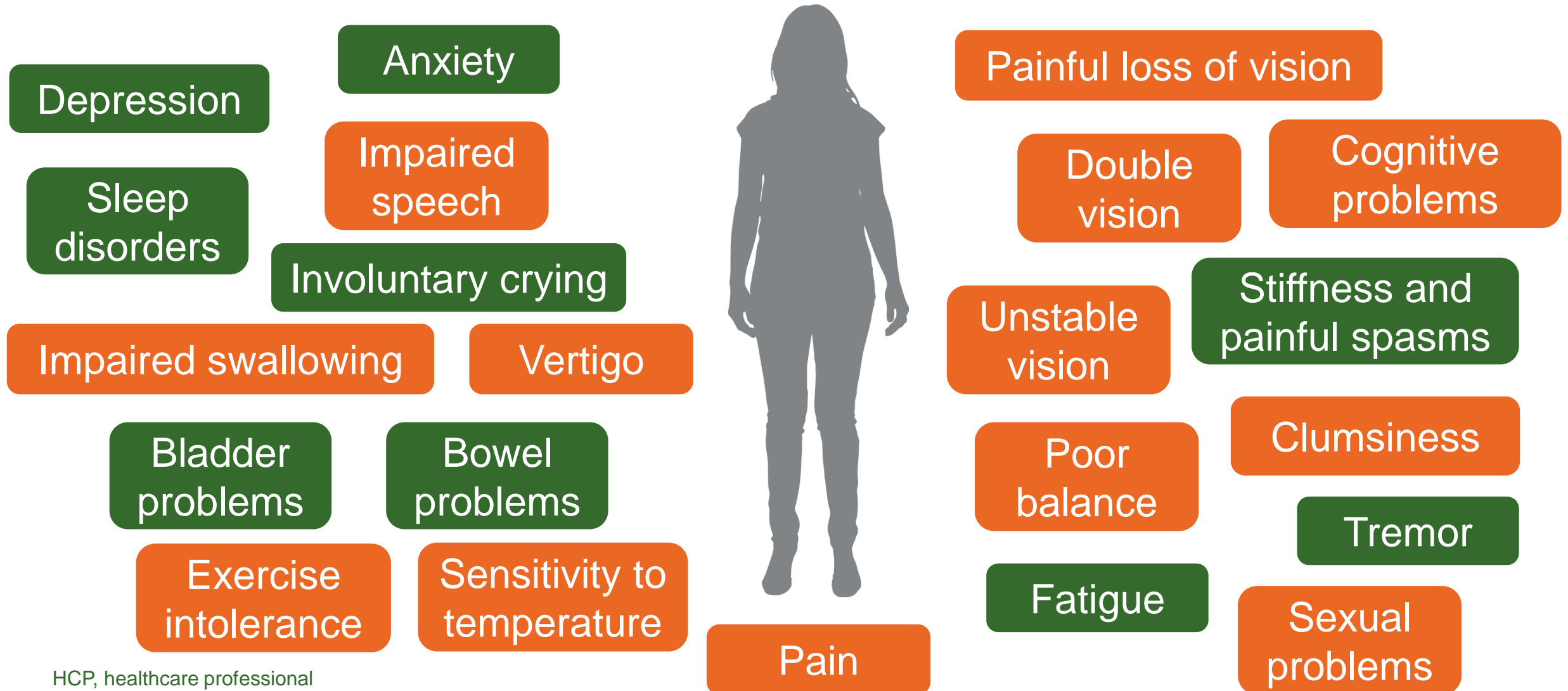
**Watch how much
you drink**



**Take medications
prescribed for
other diseases**

5. Monitoring of disease activity

Share a full picture of your health with your HCPs



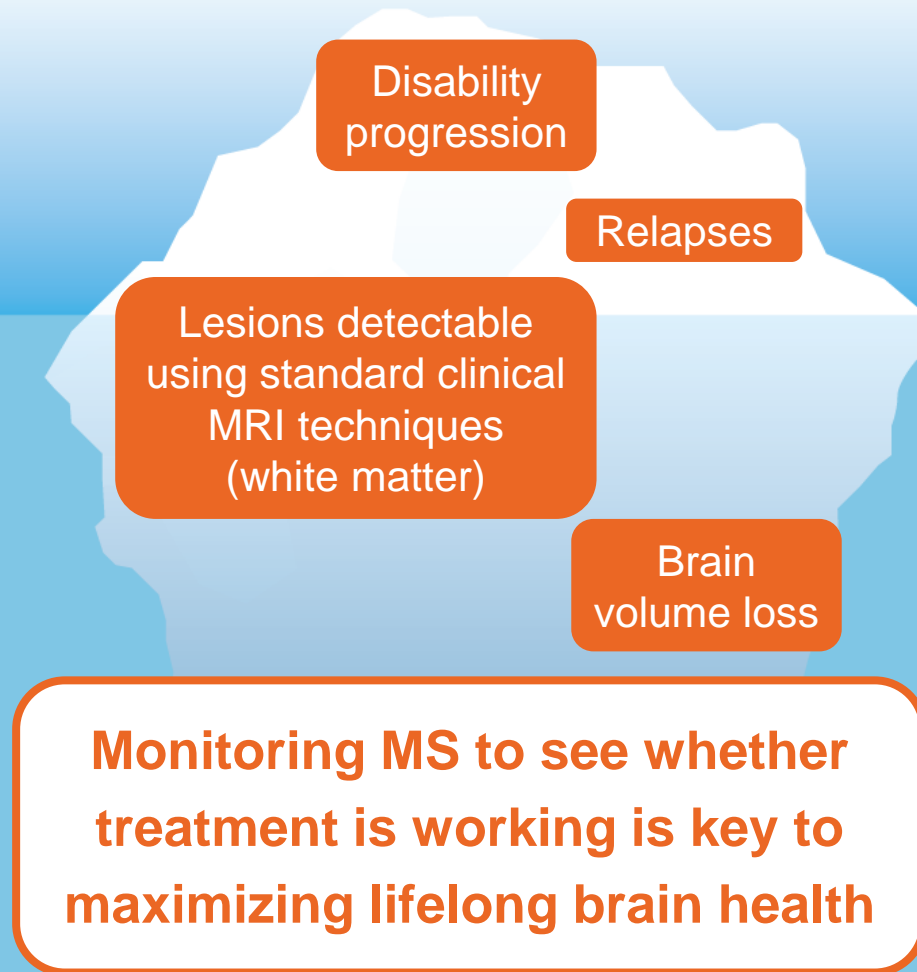
HCP, healthcare professional

5. Monitoring of disease activity

Monitoring is key to maximizing lifelong brain health



- All MS disease activity contributes to tissue loss – and therefore uses up neurological reserve – even it does not cause a relapse
- Lesions and brain volume loss (measured by MRI) predict relapses and disability progression¹
- MRI brain scans should be used to look for new lesions



- Regularly monitoring disease activity can give early warning that MS is not responding well to treatment
- MRI or clinical evidence that disease activity is poorly controlled should lead to a discussion about the possibility of switching to a DMT that acts on the body in a different way

DMT, disease-modifying therapy; MRI, magnetic resonance imaging

1. Giovannoni G *et al.* 2015. Appendix 2. *Brain health: time matters in multiple sclerosis*; pp61–63

Adapted with permission from Oxford PharmaGenesis from Giovannoni G *et al.* *Brain health: time matters in multiple sclerosis*, © 2015 Oxford PharmaGenesis Ltd.

6. Informed, shared decision-making



- Decisions about DMTs should be informed and shared between you as a person with MS, and your HCPs
- It is important to discuss your values, needs, limitations, lifestyle, treatment goals and the likely disease course with your HCPs
 - When people with MS have open, trust-based relationships with HCPs, they are more likely to continue with treatment,¹ and so are less likely to experience serious relapses²

A well-informed and proactive collaboration between you and your healthcare team is an important part of managing your MS successfully



Conclusions 1: What can you do?



Understanding the
importance of
preserving brain health

- Be aware that MS disease activity may be ongoing even when you feel well and that this can threaten brain health
- Discuss neurological reserve and brain health with others, including HCPs



Early referral
and diagnosis

- Ask for urgent referral to a neurologist if MS is suspected, preferably to one with a specialist interest in MS, or to a specialized MS clinic
- Request timely access to diagnostic procedures, including MRI
- Stay in touch with your MS team if you do not receive a diagnosis straight away

Conclusions 2: What can you do?



**Early treatment with a
disease-modifying
therapy (when
appropriate)**

- Ask your HCPs whether it is appropriate to start treatment with a DMT
- Find out what options are available



**Living a brain-healthy
lifestyle, including
treating other diseases**

- Embrace a brain-healthy lifestyle that includes keeping physically active, keeping your weight under control, keeping your mind active, not smoking, watching how much you drink and taking any prescribed medications

Conclusions 3: What can you do?



A plan to monitor MS disease activity and to switch therapy if treatment is not working

- Keep an MS diary and share this information with your HCPs
- Discuss strategies for managing your MS
- Ask the HCPs who oversee your treatment how they plan to monitor your MS
- Ensure that you feel well informed about the results of your MRI scans
- Ask whether it is appropriate to switch to another DMT



Informed, shared decision-making

- Be part of the decision-making process together with your HCPs
- Think through the important topics for discussion
- Look for other resources to help with these conversations
 - Your local MS patient organizations may be able to help



MS Brain Health
Time Matters

Our vision is to create a better future for
people with MS and their families

Your voice will help to effect this change

Commit to supporting the MS Brain Health recommendations at **www.msbrainhealth.org**

Questions and answers

All

EMSP Parallel Session III, Wednesday 18 May

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Could you be a local MS Brain Health advocate?

Christoph Thalheim

EMSP Parallel Session III, Wednesday 18 May

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Global MS initiative

- MS Brain Health is a global initiative
- With help from local advocates we can reach MSers in every country
- Could you help to raise awareness of MS Brain Health in your country?



What can you do to help?



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MS Brain Health
Time Matters

Right now ...

- Please take a few minutes to fill in the questionnaire about the slides – copy on your seat!

Questionnaire

Time matters in MS: early intervention with the most appropriate agents

Parallel session III, Wednesday 18th May, EMSP conference 2016, Oslo

Name: _____ Country: _____

Email:

1. Was the information on early intervention relevant to you?

☐ Yes ☐ No If no, please give details: _____

2. How clear was the explanation of 'brain health'? (1 – unclear, 5 – very clear)

1 2 3 4 5

3. How did the workshop make you feel? (please tick all that apply)

<input type="checkbox"/> Empowered	<input type="checkbox"/> Confident	<input type="checkbox"/> Confused	Other: _____
<input type="checkbox"/> Informed	<input type="checkbox"/> Bored	<input type="checkbox"/> Guilty	
<input type="checkbox"/> Inspired	<input type="checkbox"/> Worried	<input type="checkbox"/> Overwhelmed	

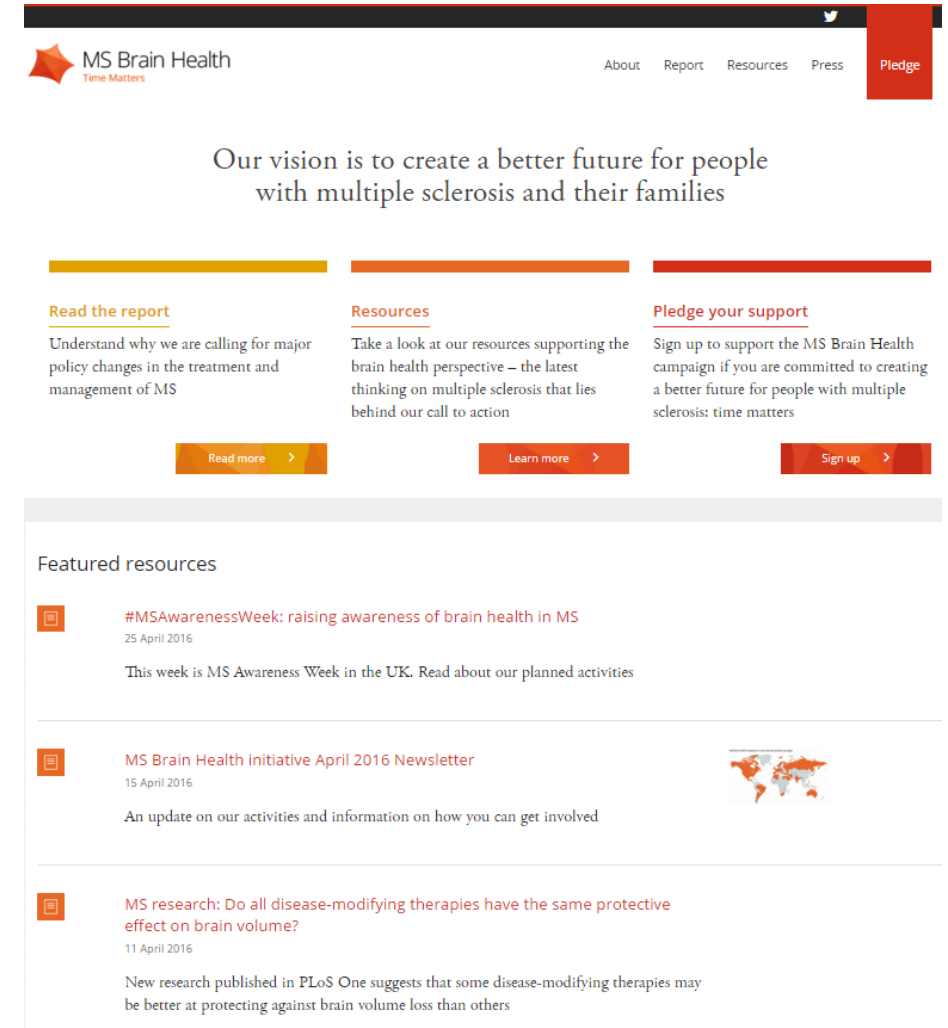
4. How realistic is it for you to live a brain-healthy lifestyle? (1 – not, 5 – very)

1 2 3 4 5

1. Learn about MS Brain Health from the website

www.msbrainhealth.org

- **Watch videos** about brain health from authors of the report
- **Read summaries** of the latest MS research
- **Download resources** for MSers, including:
 - Full report
 - Short guide (*coming soon*)
 - MS Brain Health slide set (*coming soon*)
- **Sign up** to support MS Brain Health and receive the newsletter



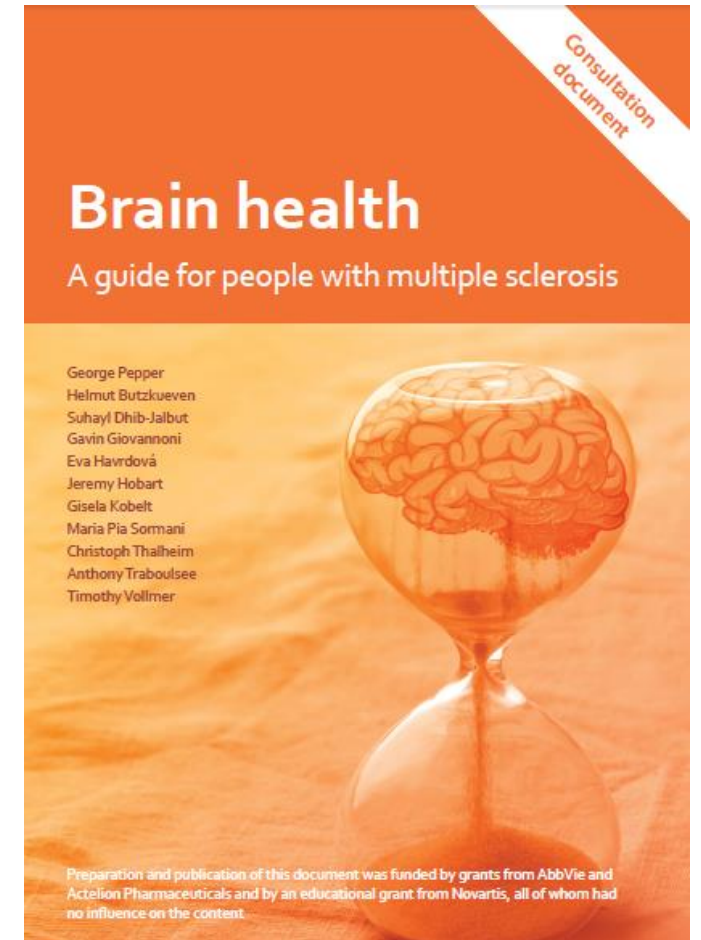
2. Spread the MS Brain Health message online

- **Follow us on Twitter @MSBrainHealth** and retweet to your followers
- **Share links on social media** to MS Brain Health videos and articles
- **Forward the newsletter** to others who might be interested



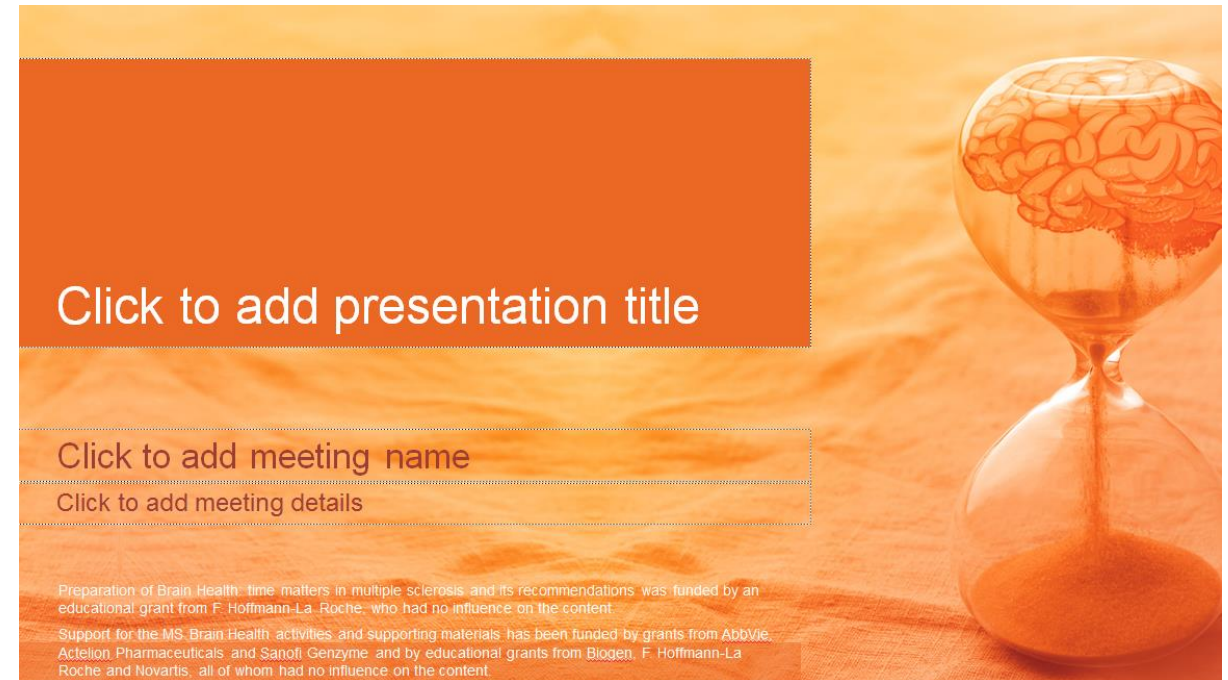
3. Give feedback on the guide for people with MS

- Take time to review your **consultation copy**
- Fill in the online survey by **Friday 27 May**
 - The link to the survey is on your guide
 - We will also email it to you
- After consultation, we will circulate the final guide
- You might like to:
 - tell your local **MS society** about the guide
 - share it with other MSers on **social media**



4. Use the MS Brain Health slides in your country

- The slides from today will be available soon on www.msbrainhealth.org
- You might like to:
 - **share** them with your local MS societies
 - **present** them at a local meeting, for example:
 - General Assembly
 - Doctor–patient information session
 - Webinar
 - **translate** them into your language



Summary of things you could do

1. Learn about MS Brain Health from the [website](#)
2. Spread the MS Brain Health message [online](#)
3. Give feedback on the [guide for people with MS](#)
4. Use the [MS Brain Health slides](#) in your country



MS Brain Health
Time Matters

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